

MENTAL HEALTH RECOVERY: WHAT HELPS AND WHAT HINDERS? A NATIONAL RESEARCH PROJECT FOR THE DEVELOPMENT OF RECOVERY FACILITATING SYSTEM PERFORMANCE INDICATORS

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Recovery Oriented System Indicators (ROSI) Measure: Self-Report Consumer Survey and Administrative-Data Profile

The ROSI is the work of the *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*. This research project evolved from collaborative efforts among a team of consumer and non-consumer researchers, state mental health authorities (SMHAs), and a consortium of sponsors working to operationalize a set of mental health system performance indicators for mental health recovery. Conceptualized and directed by five member research team (the majority of whom are primary consumers) as a three phase process (i.e., grounded theory inquiry concerning the phenomenon of recovery, creation of prototype systems-level performance indicators, and large scale pilot testing), Phase One and Two have been completed. This briefing summarizes the research process and resulting ROSI measure.

Phase One involved a grounded theory, multi-site qualitative design to identify the person-in-environment factors that help or hinder recovery for people experiencing severe and persistent mental illness. Nine SMHAs used purposive sampling to recruit 115 consumers that participated in 10 structured focus groups. Researchers used rigorous, constant and comparative analytic methods involving qualitative coding, codebook development, cross coding and recoding of the focus group transcripts to develop a single set of findings. All nine SMHAs conducted member checks with focus group participants regarding the coding report for their respective focus group. Fifty-nine (51%) of the original focus group members participated. The research achieved a “confirmability index” (agreement that the coding captured the original content) of 99.47%.

A conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery emerged from the findings. While recovery is a deeply personal journey, there are many commonalities in people’s experiences. Recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic and linked. Recovery is a product of dynamic interaction among characteristics of the individual (self-agency, holism, hope, a sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services and staff), and the characteristics of the exchange (hope, choice, empowerment, referent power, independence, interdependence). Each of these emergent domains/themes contain a rich and complex network of helping and hindering elements.

The materials herein do not necessarily reflect the positions or policies of any of the project sponsors and state research partners. The materials are based on the cumulative perspectives of 115 focus group participants, 59 member check participants, 10 think aloud participants, and 219 prototype review participants as analyzed and interpreted by the five member research team.

In Phase Two, the research team used these findings to develop recovery oriented performance indicators. Two sets emerged, 73 consumer self-report data items and 30 administrative data items. In partnership with the participating states, the team refined the self-report set based on consumer review (a Think Aloud process) and a readability check and then conducted a prototype indicator test involving a diverse cross-section of 219 consumer/survivors in seven states. The research team then used the prototype self-report data results to evaluate each item as to: (a) importance rating, (b) factor loading values within a varimax rotated component matrix, (c) response scale distribution and direction, (d) Phase One originating theme, (e) items assessing similar content, (e) clarity of wording, and (f) Phase One member check priorities. Selected demographic variables (e.g., housing status, parent status, etc.) were cross tabbed with selected item importance mean ratings to determine whether significant differences exist and therefore if an item should be retained or specified for a particular population. The research team also generated specific measure definitions (i.e., numerators and denominators) for the administrative data items. The 10 participating states and all state Directors of Consumer Affairs were then surveyed on the administrative data items as to (a) the feasibility of implementing each, (b) the importance of each for improving system recovery orientation, (c) whether or not the data articulated in the definition was currently being collected and (d) specific comments on each.

These analyses led to further refinement with an concentrated effort towards parsimony, resulting in 42 self-report items being crafted into an adult consumer self-report survey and 23 administrative-data items being crafted into an authority/provider profile for the Recovery Oriented System Indicators (ROSI) measure. A factor analysis of the 42 self-report items resulted in domains of Person-Center Decision-Making & Choice, Invalidated Personhood, Self-Care & Wellness, Basic Life Resources, Meaningful Activities & Roles, Peer Advocacy, Staff Treatment Knowledge, and Access. The 23 administrative-data items also include the domains of Peer Support, Staffing Ratios, Consumer Inclusion in Governance, and Coercion.

The ROSI bridges the gap between the principles of recovery and self-help - choice, hope, purpose, relationships, self-determination, empowerment, citizenship, resources, opportunities - and the real-world application of these principles in the everyday work of staff and service systems. The ROSI is targeted for large-scale pilot testing. A subset of these items are being incorporated into the Mental Health Statistics Improvement Program Quality Report Version 2.0, the Decision Support 2000+ and other national data collection requirements in order to generate comparable data across state and local mental health systems.

To obtain a free copy of Phase One Research Report, *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators: A National Study of Consumer Perspectives on What Helps and Hinders Recovery*, contact:

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This report is available online in PDF format at the following website: <http://www.nasmhpd.org/>. (Click on "publications," scroll to "National Technical Assistance Center for State Mental Health Planning (NTAC) Publications and Reports," scroll to "Technical Reports" and the report and appendices are under the 2002 listing.)

Recovery Oriented System Indicators (ROSI) Consumer Survey

Purpose: To provide the best possible mental health services, we want to know what things helped or hindered your progress during the past six (6) months. Please follow the directions and complete all three sections.

Section One Directions: Please read the statement and then circle the response that best represents your situation *during the last six months*. These responses range from strongly disagree to strongly agree. If the statement was about something you did not experience, circle the last response “Does not apply to me.”

1. I am encouraged to use consumer-run programs (for example, support groups, drop-in centers, etc.).	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
2. Staff respect me as a whole person.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
3. There is at least one person who believes in me.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
4. I do not have the support I need to function in the roles I want in my community.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
5. I do not have enough good service options to choose from.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
6. Mental health services helped me get housing in a place I feel safe.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
7. Staff do not understand my experience as a person with mental health problems.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
8. The mental health staff ignore my physical health.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
9. I have a place to live that feels like a comfortable home to me.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
10. Mental health services have caused me emotional or physical harm.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
11. I cannot get the services I need when I need them.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me

Please circle the response that best represents your situation *during the last six months*.

12. Mental health services helped me get medical benefits that meet my needs.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
13. Mental health services led me to be more dependent, not independent.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
14. I lack the information or resources I need to uphold my client rights and basic human rights.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
15. I have enough income to live on.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me
16. Services help me develop the skills I need.	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply To Me

Section Two Directions: Please read the statement and then circle the response that best represents your situation *during the last six months*. The responses range from never to always. If the statement was about something you did not experience, circle the last response “Does not apply to me.”

17. I have a say in what happens to me when I am in crisis.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
18. Staff believe that I can grow, change and recover.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
19. I have housing that I can afford.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
20. Staff use pressure, threats, or force in my treatment.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
21. Staff see me as an equal partner in my treatment program.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
22. Mental health staff support my self-care or wellness.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
23. Mental health services helped me get or keep employment.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
24. I have a chance to advance my education if I want to.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me

Please circle the response that best represents your situation *during the last six months*.

25. I have reliable transportation to get where I need to go.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
26. There was a consumer peer advocate to turn to when I needed one.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
27. There are consumers working as paid employees in the mental health agency where I receive services.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
28. Staff give me complete information in words I understand before I consent to treatment or medication.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
29. Staff encourage me to do things that are meaningful to me.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
30. Staff stood up for me to get the services and resources I needed.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
31. Staff treat me with respect regarding my cultural background (think of race, ethnicity, religion, language, age, sexual orientation, etc).	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
32. Staff listen carefully to what I say.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
33. Staff lack up-to-date knowledge on the most effective treatments.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
34. Mental health staff interfere with my personal relationships.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
35. Mental health staff help me build on my strengths.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
36. My right to refuse treatment is respected.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
37. My treatment plan goals are stated in my own words.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
38. The doctor worked with me to get on medications that were most helpful for me.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me

Please circle the response that best represents your situation *during the last six months*.

39. I am treated as a psychiatric label rather than as a person.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
40. I can see a therapist when I need to.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
41. My family gets the education or supports they need to be helpful to me.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me
42. I have information or guidance to get the services and supports I need, both inside and outside my mental health agency.	Never	Rarely	Sometimes	Often	Almost Always	Always	Does not apply to me

Section Three Directions: Are there other issues related to how services help or hinder your recovery? Please explain.

Recovery Oriented System Indicators (ROSI) Administrative-Data Profile

Recovery Theme: Peer Support (involves the findings that peer support and consumer operated services in a myriad of forms facilitates recovery).

Performance Indicator: Free Standing Peer/Consumer Operated Programs

Authority Measure 1: The percent of mental health catchment or service areas that have free standing peer/consumer operated programs.

Numerator: Total number of mental health catchment or service areas that have free standing peer/consumer operated programs.

Denominator: Total number of mental health catchment or service areas.

Provider Version of Measure 1: There is at least one free standing peer/consumer operated program within our community. (Yes/No)

Performance Indicator: Peer/Consumer Operated Services Funding

Authority Measure 2: The percent of state program funds allocated for peer/consumer operated services.

Numerator: The amount of program funds in the state mental health budget allocated for peer/consumer operated services during the reporting period.

Denominator: The total amount of program funds in state mental health budget during the reporting period.

Authority Measure 3: The percent of Medicaid funding reimbursed for peer/consumer delivered services.

Numerator: The amount of Medicaid reimbursement for services delivered in peer/consumer operated programs and by peer specialists during the reporting period.

Denominator: The total amount of Medicaid reimbursement for behavioral health care during the reporting period.

Performance Indicator: Consumer Employment within Mental Health Systems

Authority Measure 4: The number of annual slots specifically funded for training consumers in relevant educational and training programs and institutes to become mental health providers.

Authority Measure 5: The percent of local mental health provider agencies who have an affirmative action hiring policy regarding consumers.

Numerator: The number of local mental health provider agencies that have an affirmative action hiring policy regarding consumers.

Denominator: The total number of local mental health provider agencies.

Provider Version of Measure 5: Our agency has an affirmative action hiring policy regarding consumers. (Yes/No)

Recovery Theme: Choice (involves the findings that having choices, as well as support in the process of making choices, regarding housing, work, social, service, treatment as well as other areas of life facilitate recovery).

Performance Indicator: Advance Directives

Authority Measure 6: The percent of local mental health provider agencies that have an established mechanism to help clients develop advance directives.

Numerator: The number of local mental health provider agencies that have an established mechanism to help clients develop advance directives.

Denominator: The total number of local mental health provider agencies.

Provider Version of Measure 6: Our agency has an established mechanism to help clients develop advance directives. (Yes/No)

Performance Indicator: Involuntary Inpatient Commitments

Authority Measure 7: The percent of clients under involuntary commitments in public and private inpatient units.

Numerator: The number of clients who received involuntary inpatient commitments during the reporting period.

Denominator: The total number of clients who received inpatient services during the reporting period.

Provider Version of Measure 7: The percent of clients under involuntary commitments in inpatient units.

Numerator: The number of clients who received involuntary inpatient commitments during the reporting period.

Denominator: The total number of clients who received inpatient services during the reporting period.

Performance Indicator: Involuntary Outpatient Commitments

Authority and Provider Measure 8: The percent of clients under involuntary outpatient commitments.

Numerator: The number of clients who received involuntary outpatient commitments during the reporting period.

Denominator: The total number of clients who received outpatient services during the reporting period.

Recovery Theme: Formal Service Staff (involves the findings as to the critical roles formal service staff play in helping or hindering the recovery process).

Formal Service Staff Sub-Theme: Helpful Characteristics (involves the findings that there are certain formal service staff characteristics that are helpful to recovery).

Performance Indicator: Direct Care Staff to Client Ratio

Authority Measure 9: The ratio of direct care staff to clients within each local mental health provider agency.

Numerator: The total number of direct care staff (unduplicated) during the reporting period.

Denominator: The total number of clients (unduplicated) during the reporting period.

Provider Version of Measure 9: The ratio of direct care staff to clients within the provider agency.

Numerator: The total number of direct care staff (unduplicated) during the reporting period.

Denominator: The total number of clients (unduplicated) during the reporting period.

Recovery Theme: Formal Services (involves the findings that formal service systems' culture, organization, structure, funding, access, choice, quality, range, continuity and other characteristics can help or hinder the process of recovery).

Formal Services Sub-Theme: Helpful System Culture and Orientation (involves the finding that a formal service system's culture and orientation that is holistic and consumer oriented facilitates recovery).

Performance Indicator: Recovery Oriented Mission Statement

Authority Measure 10: The state mental health authority's mission statement explicitly includes a recovery orientation. (Yes/No).

Authority Measure 11: The percent of local mental health provider agencies whose mission statements explicitly include a recovery orientation.

Numerator: The number of local mental health provider agencies whose mission statement includes a recovery orientation.

Denominator: The total number of local mental health provider agencies.

Provider Version of Measure 11: Our agency's mission statement explicitly includes a recovery orientation. (Yes/No)

Performance Indicator: Consumer Involvement in Provider Contract Development

Authority Measure 12: The percent of provider agency performance contracts that have primary consumer involvement in their development/yearly review (specifying services, outcomes, target numbers, etc).

Numerator: The number of provider agency performance contracts documenting primary consumer involvement in their development/yearly review.

Denominator: The total number of provider agency performance contracts.

Performance Indicator: Office of Consumer Affairs

Authority Measure 13: The percent of staff in the State Office of Consumer Affairs who are former or current consumers.

Numerator: The number State Office of Consumer Affairs staff (unduplicated) who are disclosed consumers (former or current) during the reporting period.

Denominator: The total number of State Office of Consumer Affairs staff (unduplicated) during the reporting period.

Authority Measure 14: The percent of regional mental health offices/local mental health authorities (or equivalent) that have an Office of Consumer Affairs.

Numerator: The number of regional mental health offices/local mental health authorities (or equivalent) that have an Office of Consumer Affairs during the reporting period.

Denominator: The total number of regional mental health offices/local mental health authorities (or equivalent) during the reporting period.

Performance Indicator: Consumer Inclusion in Governance and Policy

Authority Measure 15: The percent of state mental health authority planning council members that are primary consumers.

Numerator: The number of primary consumers (unduplicated) who are state planning council members during the reporting period.

Denominator: The total number state planning council members (unduplicated) during the reporting period.

Authority Measure 16: The percent of local mental health provider agency board membership that are primary consumers.

Numerator: The number of primary consumers (unduplicated) who serve on local mental health provider agency boards during the reporting period.

Denominator: The total number local mental health provider agency board members (unduplicated) during the reporting period.

Provider Version of Measure 16: The percent of our agency's board membership that are primary consumers.

Numerator: The number of primary consumers (unduplicated) who serve on our board during the reporting period.

Denominator: The total number board members (unduplicated) during the reporting period.

Formal Services Sub-Theme: Coercion (involves the finding that coercion within formal service systems hinders recovery).

MHSIP's Indicators on Seclusion

Authority Measure 17: Hours of seclusion as a percent of client hours

Numerator: The total number of hours that all clients spent in seclusion.

Denominator: Sum of the daily census (excluding clients on leave status) for each day (client days) multiplied by 24 hours.

Authority Measure 18: Percent of clients secluded at least once during a reporting period

Numerator: The total number of clients (unduplicated) who were secluded at least once during a reporting period.

Denominator: The total number of unduplicated clients who were inpatients at the facility during a reporting period.

MHSIP's Indicators on Restraints

Authority Measure 19: Hours of restraint as a percent of client hours

Numerator: The total number of hours that all clients spent in restraint during a reporting period.

Denominator: Sum of the daily census (excluding clients on leave status) for each day in a reporting period (client days) multiplied by 24 hours.

Authority Measure 20: Percent of clients restrained at least once during the reporting period

Numerator: The total number of clients (unduplicated) who were restrained at least once during a reporting period.

Denominator: The total number of unduplicated clients who were inpatients at the facility during the reporting period.

Formal Services Sub-Theme: Access to Services (involves the findings as to getting the formal services that consumers feel they need and find helpful facilitates recovery).

MHSIP's Proposed Indicator on Involvement in the Criminal/Juvenile Justice System

Add Authority Measure 21: The percent of mental health catchment or service areas that have jail diversion services.

Numerator: Total number of mental health catchment or service areas that have jail diversion services.

Denominator: Total number of mental health catchment or service areas.

Provider Version of Measure 21: There are jail diversion services available within our community for mental health consumers. (Yes/No)

MHSIP's Proposed Indicator on Reduced Substance Abuse Impairment

Add Authority Measure 22: The percent of mental health catchment or service areas that have integrated substance abuse and mental health services.

Numerator: Total number of mental health catchment or service areas that have integrated substance abuse and mental health services.

Denominator: Total number of mental health catchment or service areas.

Provider Version of Measure 22: There are integrated substance abuse and mental health services available within our community for mental health consumers. (Yes/No)

Performance Indicator: Trauma Service Provision

Authority Measure 23: The percent of mental health catchment or service areas that have trauma services.

Numerator: Total number of mental health catchment or service areas that have trauma services.

Denominator: Total number of mental health catchment or service areas.

Provider Version of Measure 23: There are trauma services available within our community for mental health consumers. (Yes/No)